

# SINCE YOU CARE

IN COOPERATION WITH THE NATIONAL ALLIANCE FOR CAREGIVING

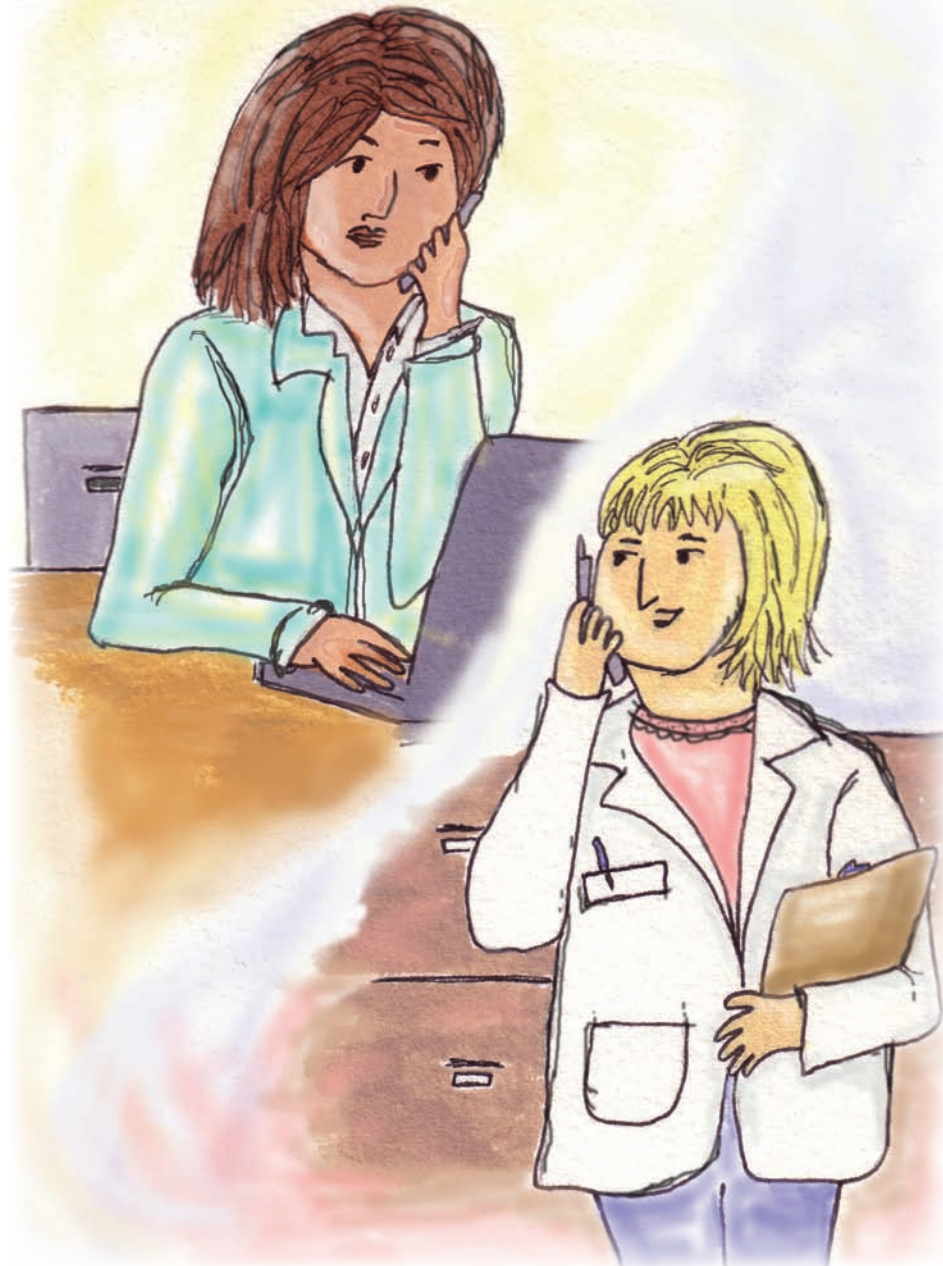
**MetLife**  
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*Caregivers face many challenges as they search for information and make decisions about how best to provide care to their loved ones. To help meet their needs, MetLife offers Since You Care® — a series of guides which provide practical suggestions and useful tools on a variety of specific care-related topics.*

## LONG DISTANCE CAREGIVING

### *About the Subject*

Advances in transportation have made us a very mobile society. People may move from place to place for a variety of reasons: to continue their education, to start a new position, to retire to a warmer climate. An adult child may move to another state to start a new job or may be transferred to another location by his or her employer. Age is not a deterrent to this mobility. In fact, within the last decade, the number of people aged 65 and older that have moved from one state to another has increased 65%.<sup>1</sup> While some may have moved to be closer to children, others may have moved to a location that more suits their retirement needs. For many people this means that family is extended not just by marriage and the addition of new members, but by actual physical distance from one member to another. It could mean that your mother may now be in the Carolinas while you're still living in Chicago. Somehow, no matter what modes of transportation are available to you, nothing shortens the distance, when you find yourself in the role of caregiver, and you are trying to care for a family member from afar.



There are some 34 million Americans providing care to older family members, with 15% of these caregivers living one or more hours from the person for whom they are providing care.<sup>2</sup> These “long distance caregivers,” in many instances, are caring for a parent or other older relative and are also employed and have dependent children of their own. In some circumstances, due to actual physical distance and/or other constraints, the long distance caregiver may be unable to provide the direct, everyday, hands-on care, but is responsible for arranging for paid care and coordinating the services that are provided.

Long distance caregivers must often juggle the demands of two households. They frequently have to rely on reports from others about daily events. Work schedules, business trips, and doctors’ appointments have to be arranged and then rearranged. Care needs have to be coordinated, services paid for, and communication channels with family members and service providers kept open. The physical and emotional demands may feel overwhelming at times.

This guide is intended to provide you with information and practical considerations as you provide assistance and support for your loved ones who live at a distance. It is important to recognize that you cannot do everything at once, that you need to take one step at a time, and most importantly that you do not need to go it alone. There are supports available that can assist both you and the family member for whom you are providing care.

## *Things You Need To Know*

The possibility that you might someday become a caregiver to a family member living at a distance from you may or may not have ever crossed your mind. In the best of circumstances, it may be a situation that has been discussed between your aging parent or relative and yourself and you will have done some planning. A more likely scenario

is that a visit to see your parent or a call from your parent’s physician or neighbor indicates a change in his or her health and the need for assistance. It may be related to a sudden event such as a stroke or a gradual process such as the onset of Alzheimer’s disease. In either instance, you may find yourself unprepared, not knowing where to begin to assist your family member. Caregiving is a process which takes time and often patience on your part. There may be rough spots along the way. Understand that each family’s experience will be different. Sometimes caregivers expect more of themselves than is reasonably possible. It is important to know that you need to allow yourself to learn as time goes on, to recognize that you may make mistakes, and to accept that things may change over time. Planning, organization, and flexibility are some of the keys to being a successful long-distance caregiver.

As a long distance caregiver you will need to determine if you will be the sole, main, or primary caregiver or if you will share the role with other relatives or friends who live closer to your family member. Being a distance from your loved one does not preclude you from being the primary caregiver, but may take a bit more ingenuity. A study by MetLife Mature Market Institute in conjunction with the National Alliance for Caregiving indicated that 23% of long distance caregivers are the sole primary caregiver.<sup>3</sup>

## *Assessing the Need*

As a first step, an assessment of your loved one’s care requirements is essential. The assessment should include both the current medical diagnosis and prognosis and an evaluation of the individual’s need for assistance. You will have to differentiate between assistance with the Activities of Daily Living (ADLs), including bathing, dressing, toileting, eating, and transferring from place to place, e.g., bed to chair, and assistance with supportive care activities such as laundry, meal preparation, shopping, managing finances, housekeeping, and

transportation, which are called Instrumental Activities of Daily Living (IADLs). The assessment must also include an evaluation of your family member's cognitive status including his or her memory, judgment, and ability to make decisions. While a care recipient's needs will change with time, the initial determination of the extent and type of assistance your family member may require and the resources you will need to provide the care are critical to beginning the planning process.

The assessment process may involve input from a variety of sources, both informal and formal. For instance, you may first notice subtle changes over time as you visit your family member. Making regular visits to aging parents or other relatives is perhaps one of the most effective ways to assess their abilities and any changes that may be occurring over time. Be observant and use your senses to help you objectively assess a situation. During visits observe the house or apartment. Note any changes that might indicate the need for assistance with the IADLs:

- Is there a change in tidiness or cleanliness?
- Is dirty laundry piling up?
- Is mail stacked on tables or desks? Are bills unopened?
- Are there smells from spoiling food or garbage?
- Is there food in the refrigerator and cupboards? Is it fresh or has it gone bad?

You may also observe signs that your family member may need assistance with the Activities of Daily Living (ADLs):

- Do you notice a change in personal hygiene?
- Does there seem to be a change in weight?
- Does he or she appear unsteady when getting up or down from the chair?
- Are there any indications of incontinence on the part of your family member, e.g. an odor of urine in the apartment or home?

You may also observe signs that your loved one is having cognitive or emotional difficulties.

- Does he or she seem to be increasingly forgetful?
- Are the shades drawn and the house dark when you arrive?
- Has your family member lessened his or her contact with family and friends?
- Does your family member appear withdrawn?
- Has he or she missed appointments or gotten lost in familiar places?
- Do there appear to be any safety risks, e.g. burnt pots in the cabinet or evidence that medications are not being taken properly?

A concerned neighbor, other family member, a health care professional, or the person in need of assistance may first bring concerns to your attention. Whatever the source of the initial concern, it is important to use whatever resources are necessary to complete the needs assessment. This may include speaking with your family member about the concerns you have or those he or she has raised. You may also gather information from friends or relatives who see your family member more frequently than you see him or her. It may involve a visit to the primary physician or a specialist to evaluate any changes in health that might be contributing to the identified problems.

Another option for a long distance caregiver is the use of a Geriatric Care Manager (GCM). A GCM is a professional specializing in the needs assessment and arrangement of services for older people. They are often nurses or social workers. The GCM can:

- make an initial assessment of care needs,
- suggest options for meeting identified needs,
- provide referrals to local resources, and
- arrange for services to be implemented.

A GCM can provide a one time service or ongoing assistance depending upon the needs of your family member and the availability of other resources to assist with needed care planning and monitoring. The care manager may be in private practice or part of a geriatric care center, senior center, or government agency, so fees will vary. You may find a GCM through the local senior center, the Area Agency on Aging, an elder law attorney, or the National Association of Professional Geriatric Care Managers website at: [www.caremanager.org](http://www.caremanager.org). Be sure to check references and determine what licenses or certifications the care manager may have. Find out the cost for the various services and determine how they are billed.

In the event of an acute event such as an illness or accident requiring hospitalization, a social worker or discharge planner at the hospital will most likely work with you and your family member to assess the need and assist with care planning upon discharge from the hospital. If your loved one is in the hospital, it is important to contact the social worker or discharge planner as soon as possible after admission to make certain a proper assessment of care needs is made and a plan for after care developed prior to your loved one leaving the hospital.

Whether the assessment is completed while your family member is at home or in a care setting, this assessment will serve as a guide to develop a plan of care to meet your family member's needs. It is important to remember, both during the assessment and care planning processes, that your family member who is in need of care should be included in the decision making process to the fullest extent that he or she is able to participate. You will want to discuss the areas of concern and potential plans to address them with your family member. If you have the services of a social worker or discharge planner available, have that person present during your discussion. Be sensitive to your family member's feelings and preferences. Acknowledge his or her desires even if they are different from your own. Be aware that help may not always initially be appreciated.

## *Developing the Care Plan*

The assessment should identify areas of need related to health care, safety, medication management, and ADL and IADL assistance. It will also look at options for both the immediate and long-term setting in which the care will be delivered. For instance, after an acute event such as a hip fracture, an individual may go to a rehabilitation unit or skilled nursing facility for short-term rehabilitation prior to returning to his or her home. In some situations, a permanent change in living environment may be needed if the care needs cannot be met in the individual's home. Moving to a new living situation, if this is needed, will involve a period of adjustment for your loved one whether that be moving to a nursing home or assisted living facility, moving to an apartment closer to where you live, or moving in with you or another relative. Most people prefer to remain in their own homes and if possible long-distance caregivers will, along with their loved one, look to develop a care plan which will make this possible. As you consider the projected care needs of your family member, think about how you can best help him or her to meet the identified needs.



The further your physical distance from your family member, the more likely you are to utilize the services of friends, family, and paid outside services to help meet the care needs. This doesn't mean you're not the primary caregiver, just that you're utilizing the resources available to you to best care for your loved one.

Do not underestimate the time that will be demanded of you as a long-distance caregiver. Studies show that nearly 50% of long distance caregivers devote one full work day a week to managing their loved one's needed services.<sup>4</sup> Almost 75% of the long distance caregivers in a 2004 study by the MetLife Mature Market Institute and the National Alliance for Caregiving indicated they were spending some 22 hours a month helping their family member with IADLs.<sup>5</sup>

It is important to mobilize whatever support is available to assist you in meeting the care needs of your loved one. Sometimes support will come from places you did not expect. Support from his or her friends and other family members begins with informing them about the situation and the potential need for their assistance. Communication with your siblings, family members, and all others who are involved in assisting or providing care, including any paid care providers, is vital to effective care planning, implementation, and monitoring. As the primary caregiver:

- Ask direct questions.
- Do not make assumptions.
- Listen to what others have to say.
- Do not be offended if your request for help is declined. Other family members may be unable or unwilling to help with a particular task, but ready and willing to do something else. For instance, you may have a sibling who does not

feel able to help with any care activities but who would be willing to assist with finances, including contacting insurance companies regarding claims and paying bills and care providers, if the family member who needs care is unable to manage these activities.

Talk about your loved one's needs with his or her friends and family who may be available to assist. If possible hold a family conference with your siblings and others. This can be an actual face to face meeting, or it might be over the telephone or through e-mails. Make a list of specific tasks that need to be accomplished and try to identify the person you feel most able to perform each task most effectively. Have measurable goals and procedures for each task for the caregivers. For example:

- Your mother's neighbor has agreed to check in on her daily, and each Wednesday evening she will call you with a week's report. In the event of an emergency, it has been agreed that she will call 911 and your sister, who lives in the same town. For personal reasons your sister wants to stay more removed from the day to day care responsibilities, but she is willing to assist in emergency situations.

Having friends and family who live near a care recipient who are willing to help with care can make long distance caregiving much less stressful. Sometimes, however, there may be very little available "informal" support or the "informal" support is not able to meet all of the identified needs. It is important to be reasonable about the level of care a neighbor or friend can provide. Depending upon the extent of the care needs and the ability of the informal support system to meet them, it may be necessary to locate some community resources and arrange for paid care.

## Locating and Implementing Community Resources

If you have a GCM assisting you or you are working with a discharge planner from a hospital, he or she will likely be able to identify community resources and help with implementing needed services. Another option for locating community resources is the **Eldercare Locator**.

The Eldercare Locator is federally funded by the U.S. Administration on Aging and provides callers with information about local services by zip code. You may call 1-800-677-1116, M-F between 9:00 a.m. and 8:00 p.m. EST or access the information on the internet at: [www.eldercare.gov](http://www.eldercare.gov). The Eldercare Locator will give you the phone number for the Area Agency on Aging (AAA) in your family member's area. The AAA is often able to either assist you in finding resources or direct you to an agency or individual who can.

Other avenues to check for information about resources include a local senior center, the local hospital social worker's office, the library, your care recipient's church affiliation, local volunteer programs, or local and national disease associations such as the American Cancer Society and the Alzheimer's Association. Obtain a local phone book to take home with you for local service agencies in your loved one's area. Alternately, accessing the internet's yellow pages may return much of the same information.

Services provided in a community will vary by location. Some services that may be offered are:

- Adult Day Services
- Home Care Services: Home Health Aides, Homemakers, Nurses, and Therapists
- Chore Services
- Transportation Services
- Friendly Visitors

- Telephone Reassurance Programs
- Meals: Congregate Sites and Delivered
- Respite Care

Once you have located community resources you must evaluate their ability to provide the services for your family member. If your family member is leaving the hospital, Medicare or other insurance may cover the cost of some or all of these in certain circumstances. For instance, Medicare may cover care for rehabilitation either at home or in a nursing facility. Services might include nursing care, therapy services, and home health aide services, as long as your family member meets Medicare criteria for skilled care. A referral for these services would likely go from the hospital to a home health care agency or a skilled nursing facility.

If your family member does not have skilled needs, you will need to look at the costs for the services that will be provided and determine how they will be covered. Costs will vary depending upon the type of care your family member requires. If your family member has a long-term care insurance policy, you should contact the company to determine what is and is not covered under the plan. The company may also be able to assist you in locating services that would be covered. Costs may vary from agency to agency. Some agencies may have a sliding fee schedule. A Geriatric Care Manager would be able to assist in locating and implementing such care or you could work with the care providers you identify directly.

If your family member is receiving care through a home care agency or another community resource, such as an adult day center, you should have the name and phone number of a supervisor whom you can call with any questions. Also make certain that the supervisor or nurse who will be overseeing his or her care has your phone number should there be an emergency or should any questions arise.



## *Keeping Important Documents in Order*

As a long distance caregiver you should also work with your family member to make certain his or her important documents and medical information are in order. Know your loved one's date of birth, Medicare and/or Medicaid number, Social Security number, and any health insurance information. Making photo copies of the birth certificate, Medicare card, Social Security card, and other important documents, laminating them, and having them in a safe place makes for easy reference.

Make sure you know the names, phone numbers, and addresses of your family member's doctor(s). If your loved one has the capacity to make decisions and wishes for you to be able to discuss concerns with the doctor, ask him or her to complete privacy release forms and have them on file with the doctor's office. This will allow the doctor to discuss with you information related to your family member's health. These releases are necessary because of privacy regulations that prohibit health care providers from sharing information with others without an individual's permission. Keep a current medica-

tion list with the name and phone number of the corresponding pharmacy on hand.

If your family member has a Will, Living Will, Financial and Health Care Power of Attorney, make copies for yourself. If these documents are not in place, your family member should speak with an attorney about the possibility of having them drawn up. These documents need to be executed while your family member still has the capacity to make these decisions. You should also have the name and contact information for his or her attorney.

While this might be a difficult area to bring up with your loved one, it would be helpful for you to know where he or she keeps financial information should you need to assist in this area in the future. This would include contact information related to his or her accountant or tax preparer as well as knowing where the financial records are kept, including copies of any insurance policies such as life insurance and long-term care insurance. It is important to recognize that your loved one may be hesitant to discuss this area with you. Sometimes individuals are uncomfortable sharing information related to their financial affairs even with those who are close to them.



## *Ongoing Care Monitoring*

Once informal and formal caregivers are in place it is important to monitor how things are going to make certain your family member's care needs are being met. This will involve your communicating with those providing the care as well as with your family member who is receiving care. Making visits, both planned and unplanned, to see how your family member is doing, speaking with staff at the agencies that are providing care, and getting updates from neighbors or other family members who may be assisting or who may see your family member on a regular basis are all important ways to monitor the care being provided and its impact on your loved one's well being. A Geriatric Care Manager (GCM) may formally monitor the care on a regular basis if you determine this level of oversight is needed and you elect to continue to use GCM services. This approach may be especially important if you are at a distance that prevents you from visiting on a regular basis and there are no family members in the area that can provide any oversight.

Expect that, with time, care needs may change or care providers who had been assisting may no longer be available. Adaptations to the care plan will need to be made in either of these circumstances. Having local resources including friends, family, and community services can greatly help the long distance caregiver both with monitoring care and with changing the care plan as needed. Using the different talents and abilities of these resources can add a degree of flexibility to a plan of care and allow for a variety of options during times of transition. If your family member's need for care increases, you may find that informal caregivers are unable to meet many of the care requirements and you will likely need to increase the amount of service from paid care providers. If you are working with a GCM or an agency that has a nurse or social worker overseeing the care your loved one is receiving, he or she would likely be able to assist you with locating additional resources.

# Long-Distance Caregiving and Other Responsibilities

## YOUR HOUSEHOLD

As you plan, implement, and monitor care for your loved one, don't forget to create a plan for your own household. Keep your family informed about your caregiving responsibilities and how it may impact them. Try to balance the needs of your family at home with the needs of the person for whom you are providing care. You may need to consider any or all of the following depending upon your family's circumstances:

- **Your children:** Make an assessment of who is available to be with your children should they need supervision or direction for school and activities. Consider a few alternates in case someone is unavailable. Determine whether these individuals can stay with the children in the event you find yourself needing to spend unscheduled or additional time with your family member who needs care.
- **Your pets:** Look into the cost and availability of local boarding kennels and pet sitters. Ask if neighbors or local relatives could also help out.
- **Have the numbers for your local newspaper and post office** if you would like deliveries held. You should also be able to request that these deliveries be put on hold by going on-line if you have their web addresses.
- **Identify a neighbor or relative who can help you** with any of the above in an emergency situation. You should also prepare a letter permitting whomever is caring for your children in your absence to give consent for medical treatment for your children, if you cannot be reached and they need care for whatever reason.

## YOUR JOB

The responsibilities of long-distance caregiving can have a significant impact on work obligations, sometimes more than anticipated. In today's economy making job changes can prove risky and threaten the financial security that many Americans have worked years to obtain. As a result many caregivers test various avenues to make the employment they have mesh with their long distance caregiving obligations.

Caregivers may be concerned that requesting changes to work schedules and obligations can threaten job security. However, many times creativity and flexibility on the job are necessary to fulfill caregiver and employee responsibilities. Caregivers may come in early so that they can leave earlier than they normally would. They may exercise the option of using personal days for caregiving. They may have to take vacation days or sick time. They may opt to take days without pay.

Employers are beginning to find that the caregiving responsibilities of their employees do impact productivity in the workplace. Today, an employer may have programs in place to assist employees in caregiving roles. As a caregiver, you may want to research what is available to you in your workplace. Some options might be:

- **Flex time:** You may be able to work 40 hours in 4 days.
- **Job sharing:** You may be able to share one full-time position with a co-worker. Sometimes this is accomplished between two employees complementing each other's schedule.

- Telecommuting or working from home one or two days a week.
- Employee Assistance Programs: These are programs that provide information and counseling for employees. Usually the Human Resources Department can provide information on this.
- Company sponsored eldercare programs which may include care management assistance or eldercare referral services available for employees who find themselves caring for an aging relative.
- The Family and Medical Leave Act (FMLA): FMLA is available to employees who work for certain employers (usually those employers with 50 or more employees) to allow up to twelve weeks of unpaid leave to eligible employees to care for certain family members for medical reasons. Some states are also enacting similar laws that will extend the duration of the FMLA. You may obtain more information on the FMLA review the details on the U.S. Department of Labor website at: <http://www.dol.gov/dol/topic/benefits-leave/fmla.htm> or call 1-866-487-2365.

## TAKING TIME FOR YOURSELF

All too often the long distance caregiver is focused on everything but his or her own needs. At any given moment it may be the kids, the job, the care recipient, the family finances. Rarely does a caregiver step back to see how he or she is doing, and all too frequently a caregiver's family and friends forget to ask. As selfish as it may seem, and even as guilty as it may make you feel, as a caregiver, you must take time for yourself.

Caring for you is not being selfish. Studies have been done on the negative effects that continual stress can have on the body. It weakens the immune system and can aggravate existing medical conditions and create new ones. It can interfere with your memory and it can cause depression. Long distance caregiving can be stressful.

In general, as a society, Americans do not like to ask for help. As a long distance caregiver, you will have to try and break with that tradition. Previous parts of this guide have suggested ways in which to enlist the help of family and outside support systems. Periodically you will need to step back and reassess the situation. For example, re-examine the tasks that you are performing. Do you need to do all of them or are there some that you can delegate to others?



Sometimes it is helpful to speak with others in similar situations to your own. You may want to consider a support group either on-line or in person. As awkward or reluctant as you may feel at first, you will find that most support group participants are experiencing or have experienced many of the emotions and frustrations that you may be feeling. It is a place where advice can be given and information exchanged. You can receive both emotional support and practical advice for addressing problems. To find a group near you, you may contact local disease specific organizations such as Parkinson's disease and Alzheimer's disease to speak with caregivers who are caring for someone with the same condition as your family member. You may also call your local Area Agency on Aging or senior center as they may be able to provide you with a listing of local caregiver support groups. The website [www.caregiver.com](http://www.caregiver.com) provides a link where you may search for both local caregiver support groups and community resources by state, county, and zip code.

Take care of your physical health. Don't ignore physical symptoms such as continual headaches, backaches, sleep disturbances, or stomach pains. Be aware of your diet and work exercise into your life. Exercise can help reduce stress and ward off depression.

Know that your emotional health is as important as your physical health. Give yourself credit for what you are doing. Recognize what you can and can't change and act on what you can. Set limits and learn to say no to friends, family, or the care recipient. Forgive yourself for not being perfect. Don't let yourself become isolated from friends, family, and activities that you've always enjoyed.

If necessary, let people know that you need them to include you and not to be put off if initially you decline an invitation. Ask them to be persistent, for your sake.

Be willing to acknowledge the signs that you may need some help or more help than you are presently receiving:

- Signs of depression, hopelessness, lack of energy to do new things, feelings of being alone

- Chronic fatigue
- Sleeplessness
- Excessive use of alcohol, sleeping pills, or other medications
- Changes in appetite
- Feelings of helplessness, panic attacks, unexplained anxiety
- Unexplained mood swings, irritability.

Check with a health care professional or counselor if you have concerns or others are voicing concerns about you. It's not a sign of weakness to ask for help, but rather an indication of a strong individual who's willing to accept limitations and reach out to those people and for those services that provide the very best for themselves and the person they care for.

## *Helpful Hints*

- Communication is key for all involved. You may want to set regular times to check in with the family member for whom you are caring and with those who are providing care. This may help to cut down on multiple calls back and forth between you and those you are trying to reach.
- If your family member lives alone, you may want to obtain a personal emergency response system so that he or she can call for help in the event of an emergency. The system would typically have your family member wear a watchlike band or pendant with a button he or she can hit should emergency assistance be needed, e.g. if your loved one has fallen. For more information on this product and its features as well as the costs involved you can go to [www.alertusa.org](http://www.alertusa.org) or [www.lifelinesys.com](http://www.lifelinesys.com) or call Lifeline at 1-800-380-3111.

- Try to make time for some of the things you enjoy doing: going out to dinner, spending an evening with friends or going to the movies.
- Keep a list handy of chores/services that can be delegated if someone asks “What can I do for you?” You won’t have to think about what needs to be done and it allows the other person a free choice of service.
- You may want to photo copy your loved one’s address book to keep important phone numbers handy for your reference at home, when you are not with your family member and need to make calls on his or her behalf. Add any important numbers and information that may be missing. This would include the names, addresses, and e-mail addresses as well as the phone numbers for utilities, doctors, police, fire department, bank, attorney, plumber, handyman, etc., and service providers being used as well as others available in your loved one’s area.
- Depending upon the mode of transportation you utilize when visiting your loved one, keep a laminated index card in your purse or wallet that has the numbers that would be important for you to have for traveling, such as the local taxi or bus service to nearby airports; the schedules, 800#s and website addresses for the airlines, buses, and trains that you use when you travel to your loved one’s area.

Medicare and Medicaid, and legal issues related to caring for aging parents. It also includes information on changes in healthcare and Social Security laws. American Bar Association (2006), Random House Reference, \$16.95, ISBN: 0375721398

### **AND THOU SHALT HONOR: THE CAREGIVER’S COMPANION**

This book provides information and practical support to anyone in a caregiver’s role. It also includes checklists and a resource directory as well as advice and suggestions from both experts and “every day” caregivers. McLeod, B. (Editor), (2003). Rodale Books, \$15.95, ISBN: 1579547745

### **CARING FOR YOUR PARENTS: THE COMPLETE AARP GUIDE**

This book discusses innovative ways that others have approached caregiving issues and concerns. It explores a variety of caregiving topics, includes many helpful tips, and contains a listing of resources related to each chapter. It includes information related to caring from a distance, organizing a family meeting, taking care of your own needs. Delahanty, H., Ginzler, E. and Pipher, M. (2005), AARP, \$19.95, ISBN: 1402717393

### **THE FEARLESS CAREGIVER: HOW TO GET THE BEST CARE FOR YOUR LOVED ONE AND STILL HAVE A LIFE OF YOUR OWN**

This book includes written contributions from both professional and family caregivers. It explores a variety of caregiving issues and the important role the family caregiver plays in the plan of care for a loved one. It provides helpful tips surrounding a variety of caregiving issues and focuses on the needs of the caregiver as well as the care recipient. Barg G.(editor)(2003), Capital Books, \$15.95, ISBN:1931868565

## *Resources to Get You Started*

### *Books and Publications*

#### **THE AMERICAN BAR ASSOCIATION LEGAL GUIDE FOR AMERICANS OVER 50**

This guide covers many legal questions and issues facing older Americans and can serve as a helpful tool for the long-distance caregiver. Topics include advance planning for health care decisions, wills, trusts,

## HOW TO CARE FOR AGING PARENTS

This book is a useful starting point for those finding themselves in a caregiver's role for parents or any other older relative. It provides information on healthcare issues, caregiver concerns, community and facility based services as well as an extensive listing of helpful agencies and organizations, with contact information. Morris, Virginia, Workman Publishing Company; (2004), \$18.95, ISBN: 0761134263

## SO FAR AWAY: TWENTY QUESTIONS FOR LONG-DISTANCE CAREGIVERS

This free guide from the National Institute on Aging is specifically designed for long-distance caregivers and looks at twenty key areas to think about in a question and answer format. In addition to providing helpful information and tips, it includes a list of useful resources with contact information.

It can be downloaded and printed or ordered at: [www.nia.nih.gov/HealthInformation/Publications/LongDistanceCaregiving/](http://www.nia.nih.gov/HealthInformation/Publications/LongDistanceCaregiving/). It can also be ordered by calling toll-free at 1-800-222-2225.

Janice Lynch Schuster (author), National Institute on Aging, National Institutes of Health, U.S. Department of Health and Human Services, NIH Publication No. 05-5496, January 2006.

## *Internet Sites*

### ADMINISTRATION ON AGING (AOA)

AOA is maintained by the U.S. Department of Health and Human Services, and provides resources, news and developments, and other information for older adults. The AOA's home page may be accessed at: [www.aoa.gov](http://www.aoa.gov).



## **AGENET-SOLUTIONS FOR BETTER AGING**

This site provides searchable databases for organizations, services, and eldercare assistance. It includes a number of useful checklists around topics such as home safety, medication assessment, nursing homes, and assisted living. It also provides online shopping for eldercare products and supplies. Access the site at: [www.agenet.com](http://www.agenet.com) or call 1-888-405-4242, M-F, 7 a.m. to 5 p.m. CST to speak with a representative about eldercare products that are available.

## **AGING CARE.COM**

Agingcare.com is a website established to provide caregivers with information and assistance related to a variety of caregiving issues. It includes advice from experts, tips on locating and evaluating care, aging related news, and a message board where individuals can exchange information on a variety of caregiving topics. The site can be accessed at [www.agingcare.com](http://www.agingcare.com).

## **BENEFITSCHECKUP**

This site was developed by the National Council on Aging (NCOA) and can assist aging adults and their families in determining benefit eligibility for services in their area. Access the site at: <http://www.benefitscheckup.org/>.

## **THE COMMISSION ON LAW AND AGING OF THE AMERICAN BAR ASSOCIATION**

The Commission on Law and Aging of the American Bar Association website at: [www.abanet.org/aging](http://www.abanet.org/aging) provides valuable information for consumers, including *A Consumer's Toolkit for Health Care Advance Planning* which can be downloaded and printed from the site. Search under "Publications" and click on "Consumer Publications on-line" to access the toolkit. The site also provides the ability to search for legal and other aging resources on a state by state basis at: [www.abanet.org/aging/resources/statemap.shtml](http://www.abanet.org/aging/resources/statemap.shtml).

## **FAMILY CAREGIVER ALLIANCE (FCA)**

FCA provides information, education, services, research and advocacy for the nation's caregivers. Based in California, it provides national, state, and local levels of support. You can contact FCA by calling 1-800-445-8106 M-F, 9 a.m. - 5 p.m. PST (Please note the office is closed from 12:00 to 1:00 p.m. PST). The site includes a 50-state searchable resource map: Family Care Navigator,<sup>SM</sup> which provides state specific information on resources and programs to assist individuals and their caregivers. Informational fact sheets and publications are available on-line, including a *Handbook for Long-Distance Caregivers*. They can be downloaded and printed. Access the site at: [www.caregiver.org/caregiver/jsp/home.jsp](http://www.caregiver.org/caregiver/jsp/home.jsp).

## **NATIONAL ALLIANCE FOR CAREGIVING**

The National Alliance For Caregiving website includes research on caregiving as well as practical assistance for caregivers including tip sheets. It can be accessed at [www.caregiving.org](http://www.caregiving.org).

This website also currently includes a link to a public educational website for caregivers which is co-sponsored by the National Alliance for Caregiving and the National Family Caregivers Association with funding by Eisai Inc. This website provides assistance and information for family caregivers on a variety of issues related to caregiving as well as resources for locating needed services. The website can be accessed directly at [www.familycaregiving101.org](http://www.familycaregiving101.org).

## **STRENGTH FOR CARING**

The Strength for Caring website provides a wealth of information for caregivers on topics such as medical diagnoses, financial planning, legal issues, insurance, and daily care. It includes the ability to download and print caregiving brochures from a variety of organizations and has a listing of statewide and local caregiving and healthcare resources as well as support information for each of the 50 states. [www.strengthforcaring.com](http://www.strengthforcaring.com)

# CAREGIVER EMERGENCY INFORMATION

**Name of Care Recipient:** \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

**Primary Emergency Contact:** \_\_\_\_\_ Relationship: \_\_\_\_\_

Phone (Home): \_\_\_\_\_ (Work): \_\_\_\_\_ (Cell): \_\_\_\_\_

Email Address: \_\_\_\_\_

Residential Address: \_\_\_\_\_

**Secondary Emergency Contact:** \_\_\_\_\_ Relationship: \_\_\_\_\_

Phone (Home): \_\_\_\_\_ (Work): \_\_\_\_\_ (Cell): \_\_\_\_\_

Email Address: \_\_\_\_\_

Residential Address: \_\_\_\_\_

## Service Providers (e.g. Home Health Care Agency, Adult Day Center, Nursing Home):

1. **Type of Agency or Facility:** \_\_\_\_\_

Name of Agency or Facility: \_\_\_\_\_

Phone: \_\_\_\_\_

Contact: \_\_\_\_\_

Days that care is provided: \_\_\_\_\_

Hours that care is provided: \_\_\_\_\_

2. **Type of Agency or Facility:** \_\_\_\_\_

Name of Agency or Facility: \_\_\_\_\_

Phone: \_\_\_\_\_

Contact: \_\_\_\_\_

Days that care is provided: \_\_\_\_\_

Hours that care is provided: \_\_\_\_\_

## Individuals Providing Care:

1. **Name:** \_\_\_\_\_

Phone (Home): \_\_\_\_\_ (Work): \_\_\_\_\_ (Cell): \_\_\_\_\_

Days and hours of care: \_\_\_\_\_

2. **Name:** \_\_\_\_\_

Phone (Home): \_\_\_\_\_ (Work): \_\_\_\_\_ (Cell): \_\_\_\_\_

Days and hours of care: \_\_\_\_\_

**Primary Physician:** \_\_\_\_\_ **Other Physician (Specialist):** \_\_\_\_\_

Phone: \_\_\_\_\_ Specialty: \_\_\_\_\_

Fax: \_\_\_\_\_ Phone: \_\_\_\_\_

Fax: \_\_\_\_\_

**Hospital Information: Name:** \_\_\_\_\_

Phone (Admitting): \_\_\_\_\_ (Emergency): \_\_\_\_\_

Family Member's Phone: \_\_\_\_\_ (Nurse's Station): \_\_\_\_\_

Other Contact (e.g. Discharge Planner) Name: \_\_\_\_\_ Phone: \_\_\_\_\_

**Person DOES \_\_\_\_\_ OR DOES NOT \_\_\_\_\_ have a Living Will**

**Person DOES \_\_\_\_\_ OR DOES NOT \_\_\_\_\_ have a Health Care Power of Attorney**

(You should maintain a copy of these documents)

**Insurance Plan Name:** \_\_\_\_\_

• Member Number: \_\_\_\_\_

• Group Number: \_\_\_\_\_

• Medicare: Part A: \_\_\_\_\_ Part B: \_\_\_\_\_

(Keep a copy of insurance cards)

**Current Medications: (include nonprescription/over the counter):** \_\_\_\_\_

Medication: \_\_\_\_\_ Dose: \_\_\_\_\_ Frequency: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Vitamins/Herbal Supplements:** \_\_\_\_\_

**Allergies:** Drugs: \_\_\_\_\_ Food/Other: \_\_\_\_\_

**Pharmacy:** (Name): \_\_\_\_\_ (Address): \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

**Existing Medical Conditions:**

1) \_\_\_\_\_ 2) \_\_\_\_\_

3) \_\_\_\_\_ 4) \_\_\_\_\_

5) \_\_\_\_\_ 6) \_\_\_\_\_

**Other Notes:** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# PERSONAL EMERGENCY INFORMATION

Personal Emergency Information (This tool is intended to be kept at the care recipient's home. It contains contact information and important information about the care recipient's health. It should be kept in a place that is easily accessible, one that all caregivers are aware of, so that it can be retrieved and given to healthcare professionals if emergency treatment is needed or the individual is seeing a new doctor.)

**Name:** \_\_\_\_\_ **Date of Birth:** \_\_\_\_\_

**Address:** \_\_\_\_\_ **Phone:** \_\_\_\_\_

**Primary Emergency Contact:** \_\_\_\_\_ **Relationship:** \_\_\_\_\_

**Phone (Home):** \_\_\_\_\_ **(Work):** \_\_\_\_\_ **(Cell):** \_\_\_\_\_

**Email Address:** \_\_\_\_\_

**Residential Address:** \_\_\_\_\_

**Secondary Emergency Contact:** \_\_\_\_\_ **Relationship:** \_\_\_\_\_

**Phone (Home):** \_\_\_\_\_ **(Work):** \_\_\_\_\_ **(Cell):** \_\_\_\_\_

**Email Address:** \_\_\_\_\_

**Residential Address:** \_\_\_\_\_

**Primary Physician:** \_\_\_\_\_

**Phone:** \_\_\_\_\_ **Fax:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Other Physician (Specialist):** \_\_\_\_\_

**Specialty:** \_\_\_\_\_

**Phone:** \_\_\_\_\_ **Fax:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Other Physician (Specialist):** \_\_\_\_\_

**Specialty:** \_\_\_\_\_

**Phone:** \_\_\_\_\_ **Fax:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Hospital for Admissions:** \_\_\_\_\_

**Phone (Admitting):** \_\_\_\_\_ **(Emergency):** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Person DOES** \_\_\_\_\_ **OR** **DOES NOT** \_\_\_\_\_ **have a Living Will\***

**Person DOES** \_\_\_\_\_ **OR** **DOES NOT** \_\_\_\_\_ **have a Health Care Power of Attorney\***

\*Copies of these documents should be kept with this form and given to healthcare professionals if emergency treatment is needed or the individual is seeing a new doctor.

(Perf line - Does not print.)

**Insurance Plan Name:**

- Member Number: \_\_\_\_\_
- Group Number: \_\_\_\_\_
- Medicare: Part A: \_\_\_\_\_ Part B: \_\_\_\_\_
- Insurance Cards: Yes\* \_\_\_\_\_ No \_\_\_\_\_

**Current Medications: (include nonprescription/over the counter):**

Medication: _____	Dose: _____	Frequency: _____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

**Vitamins/Herbal Supplements:** \_\_\_\_\_  
\_\_\_\_\_

**Allergies:** Drugs: \_\_\_\_\_ Food/Other: \_\_\_\_\_

**Pharmacy:** (Name): \_\_\_\_\_ (Address): \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

**Existing Medical Conditions:**

- 1) \_\_\_\_\_ 2) \_\_\_\_\_
- 3) \_\_\_\_\_ 4) \_\_\_\_\_
- 5) \_\_\_\_\_ 6) \_\_\_\_\_

**Other Notes:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**ALL INFORMATION WAS LAST UPDATED ON:** \_\_\_\_\_

\*Copies of these documents should be kept with this form and given to healthcare professionals if emergency treatment is needed or the individual is seeing a new doctor.

(Perf line - Does not print.)

# Useful Tools

Enclosed are tools to help you start a written record of information:

- **Caregiver Emergency Information** – This tool is intended for the caregiver to keep at his or her home. It includes important contact information should calls need to be made on behalf of the caregiver’s family member.
- **Personal Emergency Information** – This tool is intended to be kept at the care recipient’s home. It contains contact information and important information about the care recipient’s health. It should be kept in a place that is easily accessible, one that all caregivers are aware of, so that it can be retrieved and given to healthcare professionals if emergency treatment is needed or the individual is seeing a new doctor.

## Endnotes

<sup>1</sup> *Long Distance Caregiving*, University of California, Santa Barbara, (USCB) Human Resource Department, via the internet at: [http://hr.ucsb.edu/worklife/elder\\_care\\_longdistance.php](http://hr.ucsb.edu/worklife/elder_care_longdistance.php), accessed via the internet 8/08.

<sup>2</sup> *Caregiving in the U.S.*, National Alliance for Caregiving and AARP, 2004.

<sup>3</sup> *Miles Away: the MetLife Study of Long Distance Caregiving*, MetLife Mature Market Institute & National Alliance for Caregiving, July 2004.

<sup>4</sup> Ibid.

<sup>5</sup> Ibid.





## ABOUT THE AUTHORS OF SINCE YOU CARE®

*Since You Care* guides are prepared by the MetLife Mature Market Institute in cooperation with the National Alliance for Caregiving and MetLife's Care Coordinators.

### **MetLife Mature Market Institute®**

Established in 1997, the Mature Market Institute (MMI) is MetLife's center on aging and the 50+ market. MMI's groundbreaking research, gerontology expertise, national partnerships, and educational materials work to expand the knowledge and choices for those in, approaching, or caring for those in the mature market.

MMI supports MetLife's long-standing commitment to identifying emerging issues and innovative solutions for the challenges of life. MetLife, a subsidiary of MetLife, Inc. (NYSE: MET), is celebrating 140 years and is a leading provider of insurance and financial services to individual and institutional customers.

For more information about the MetLife Mature Market Institute, please visit their website at [www.MatureMarketInstitute.com](http://www.MatureMarketInstitute.com).

57 Greens Farms Road  
Westport, CT 06880  
E-Mail: [MatureMarketInstitute@metlife.com](mailto:MatureMarketInstitute@metlife.com)

**MetLife Care Coordinators** are available to MetLife's long-term care customers and their caregivers to help identify and resolve caregiving questions and concerns through counseling and referral.

### **National Alliance for Caregiving**

Established in 1996, the National Alliance for Caregiving is a nonprofit coalition of national organizations that focuses on issues of family caregiving across the life span. The Alliance was created to conduct research, do policy analysis, develop national programs, and increase public awareness of family caregiving issues.

4720 Montgomery Lane,  
Fifth Floor, Bethesda, MD 20814  
[www.caregiving.org](http://www.caregiving.org)

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*This booklet offers general advice, however, it is not a substitute for consultation with an appropriate professional. Please see a health care professional, attorney, or other appropriate professional when determining how the information and recommendations discussed in this booklet apply to your specific situation.*